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AUTHOR Kallstrom, Lee A.
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ABSTRACT

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# SERVING THE DEVELOPMENTALLY DISABLED AGED

Paper presented at the
First World Congress on Future Special Education
Council for Exceptional Children
Stirling, Scotland, June, 1978

Panel Session - 1:30 to 3:30 p.m., Tuesday, June 27, 1978
"The Care, Education and Treatment of the Handicapped"
Paper: Approximately 15 minutes

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Author: Lee A. Kallstrom
Assistant Professor
Special Education and
Gerontology
University of Nebraska at Omaha
Omaha, Nebraska, USA

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ABSTRACT

Increasing numbers of aging developmentally disabled individuals have led to a recent emphasis being placed on service provision of this population, the education of professionals working with these populations, and the assessment of current conditions and needs of these individuals. Through the University Affiliated Program, a project of national significance has begun to investigate the educational needs of service professionals and the needs of the aging developmentally disabled in long term care centers and in the community.

# SERVING THE AGING DEVELOPMENTALLY DISABLED

As I reviewed Dr. Callahan's paper on Futurism prior to coming to the Congress, it was not at all difficult to relate his concepts and ideas to populations of aging, developmentally disabled. For the future is nearly all that exists within this field. The special and particular needs manifest by this population, along with a lack of knowledge and information available, and finally the concept that the population is in its infancy gives a great latitude of concerns to discuss as future considerations.

Traditionally, service programs, research, and the training of professionals involved with the developmentally disabled have emphasized and focused on the needs of children and adolescents. However, as a result of improvements in medical and health care, improved living conditions, and generally improved service provision, the developmentally disabled individual is beginning to live longer. The specific needs of this population are often unique and must be addressed from a unique point-of-view. New alliances between disciplines must be formed, modifications in the education of service personnel must be made and access to information regarding this population, which is currently unavailable, will be needed.

Recognizing these needs, the Developmental Disabilities Office of the Department of Health, Education, and Welfare, in 1976, funded

five University Affiliated Programs (UAP), for three years each, to address the specific needs and services necessary for the aging developmentally disabled populations. The programs include a national emphasis: each of five states; Oregon, Utah, Georgia, Michigan, and Nebraska were awarded three-year grants.

These grants were designed to collect, analyze, and disseminate information on the older and aged developmentally disabled. Also, responsibility was given for developing training materials and programs within university and community settings. Through these efforts, the projects hope to influence policy and planning, and to identify, enhance, or develop the skills and expertise of all persons working with the older and aged developmentally disabled person.

One of the initial goals of the five institutions was the collection and colation of existing materials and references to service provision which approached the individual who was aging and developmentally disabled. Minimal information was uncovered. In retrospect, this is not too surprising, in that since this population had not, in the past been defined as a group: 1) they were not seen as part of the "...increasingly vocal non-disabled elderly population", 2) they have not had a visible place in the planning for the developmentally disabled population." (N. Thomas, p. 2). Another initial goal was defining terminology to be used. At this time, (June, 1978), although still undergoing change, the following definitions are currently in use:

The <u>older (aging)</u> individual is considered to be anyone who has reached physical maturity.

The aged person includes all individuals whose chronological age is 55 and who are eligible for services to senior citizens.

Finally, developmentally disabled individuals are persons with cerebral palsy, epilepsy, mental retardation, or autism, manifested during the developmental period prior to age 18. (This definition, by the way, is the current legal definition which is undergoing modification to replace the named categories with a set of functional criteria).

With these definitions in mind, let me discuss the goals of one constituent, the Nebraska Project, which I have had the opportunity to coordinate.

The Nebraska Project is the only one of the five which is housed in a Gerontology component within the UAP. The Gerontology Program is a problem-centered rather than discipline-centered unit within the University of Nebraska system. This allows for a multidisciplinary approach rather than the more usual discipline-centered base. Students in the program typically major in a number of areas such as counseling, social work, psychology, special education, or public administration while at the same time obtaining a certificate of specialization in gerontology. Gerontology courses are often cross-listed between two or more departments and faculty are utilized with a broad range of expertise, experience and interests.

Two major areas of emphasis were undertaken within this project: first, to design and develop a comprehensive curriculum program for potential service personnel working with the aging/developmentally

disabled, including the development of credit and non-credit courses, workshops, and inservices for dissemination at local, state, and regional levels, and second, to provide technical assistance to agencies and organizations concerned with service provision to the aging developmentally disabled. These two goals were designed to improve the professional practices and quality of care extended by the community to the older developmentally disabled populations.

At this point, two years into the proposed three year project, the surface has been scratched. As a part of the curriculum development within the university system and within the community, a number of credit courses have been developed and/or modified to include information pertinent to the aging/developmentally disabled population. These courses cover a broad base of departments and colleges, including: psychology; counseling and guidance; social work; health education; recreation; and special education. The response from the various departments has been excellent, indicating that the recognition of the problem was enough to motivate the revision and/or addition to the curriculum offerings. Many of these departments are recognizing that they have a common concern, the aging/developmentally disabled population.

Also, the request for inservice and workshops on aging/developmentally disabled is ever increasing and this type of educational experience is on the rise, at least in Nebraska.

Another important aspect of the project is the assessment of the community to determine what needs exist, how these needs are

being met, and what steps can be taken to improve the existing services provided to the aging/developmentally disabled. In conjunction with one of the foremost community based service agencies in the USA, the Eastern Nebraska Community Office of Retardation, commonly known as ENCOR, an assessment was conducted of all individuals who could be located in a five county region in eastern Nebraska.

The following conclusions were reached based upon initial findings from the survey: (Wood, 1978)

1. If you are older and developmentally disabled, you are probably institutionalized. You have only about one chance in four of living in a non-institutional setting.
2. If you are developmentally disabled and residing in a nursing home, you have nearly a 50-50 chance that you could have your needs met using currently available resources in the community. Forty-nine percent of the surveyed population could have been served by existing community services. The other 50% could almost all be served in less restrictive settings, if new programs and supports were developed.
3. If you are developmentally disabled and residing in a nursing home, you are probably self-reliant in your self-care skills. The majority of the persons labeled "severely disabled" who reside in nursing homes are fairly self-reliant, for example:
   a. 73% eat without help,

b. 67% are ambulatory,

c. 84% have normal hearing,

d. 51% dress themselves without assistance,

e. 74% have normal vision,

f. 58% can toilet themselves independently, etc.

4. If you are developmentally disabled and reside in a nursing home, you probably have little contact with family or friends. Nursing home placement tends to break off social contracts, for example:

   a. 40% of those residing in nursing homes never have a visit from their family and only 27% have such visits even occasionally;

   b. 59% never have visits from firends and only 26% have such visits occasionally.

The Nebraska Study is an initial attempt to quantitatively assess current needs and services available to aging/developmentally disabled population in the area. This is appropriate for Nebraska as we have one of the highest longevity expectencies in the United States. We are anxious to complete this study as it will have an important effect on the directions which research and service provision will take in the not too distant future.

Looking forward from this point in 1978, some of the same questions must be asked as were originally posed by Dickerson in 1974. The thrust of the five projects concerned with aging and developmental disabilities will continue to be directed toward solutions and

answers to these problems:

1. Do the mentally retarded tend to age more quickly than the normal population? It was noted that many mentally retarded individuals tend to become prematurely old. There seems to be a noticeable physical deterioration in their health condition (i.e., loss of teeth, etc.). Is this premature aging process directly related to the factors of mental retardation (i.e., chromosomal disorders, etc.) or is it due to poor medical and health care?
2. To what degree is the aging process of the mentally retarded more pronounced because, historically, they have not learned self-care skills or have severe limits placed on their educational opportunities?
3. Do the aged mentally retarded residing in state institutions tend to live longer than the aged mentally retarded residing in the community?
4. At times, it is difficult to find the mentally retarded aged once they have been discharged from state institutions. For example, when they are placed in a nursing home their records often do not follow them and the staff often are unaware of their background or specific needs. What kinds of organizational procedures need to be devised to help the community resources be more aware of the special needs and background of this population? Sometimes an aged retarded person might be placed in a small group home and subsequently forgotten since little, if any, follow-up is ever undertaken.

5. Why have so few surveys been undertaken to carry out case findings regarding the identification of the aged retarded in the community?

6. It appears that while much concern has been expressed about preparing the normal person for the aging process, little thought has been given to preparing the adult retarded for old age. There is a need to develop programs in state institutions and in community group homes that prepare the adult retarded person to handle the problems that may arise during the aging process.

7. To what degree are the mentally retarded aged different from the more normal aged person? Some professionals and agency personnel contend the problems of the aged retarded are similar to the problems of the normal aged and therefore, no special concern or attention is required relative to the needs of the mentally retarded aged. This view has serious implications for the development of specialized programs for the aged retarded.

Much needs to be done. Admittedly, the area is in its infancy. Perhaps you can raise other questions and/or concerns which have not been raised.

## REFERENCES


Callahan, William G., "Futurisms: A Question-Answer Approach for Beginners in the Field", paper distributed to all participants, First World Congress on Future Special Education, Stirling, Scotland, June, 1978.

Dickerson, Martha; Jane Hamilton; Robert Huber; and Robert Segal, "The Aged Mentally Retarded: The Invisible Client: A Challenge to the Community", paper presented at The Annual Meeting of the American Association on Mental Deficiency, Toronto, Canada, 1974.

Thomas, Nola, "Aging and Aged Developmentally Disabled People: Defining a Service Population", unpublished paper, 1978.

Wood, E. James, "Comparison of Community vs. Nursing Home Services for Developmentally Disabled Aged", paper presented at the Annual Meeting of the American Association of Mental Deficiency, Denver, Colorado, May, 1978.

QUARTERLY PROGRESS REPORT

April 1, 1978 to June 30, 1978

# GERONTOLOGICAL ASPECTS OF DEVELOPMENTAL DISABILITIES

Project Number: 54-P-71151/7-02

Project Director: David A. Peterson, Ph. D.

Gerontology Program
University of Nebraska at Omaha
Omaha, Nebraska 68182

Gerontological Aspects of Developmental Disabilities has completed the goals set for June 30th and has made considerable advancement in other aspects of the project which are developing on schedule.

OBJECTIVES TO DATE

1. To continue development of curriculum within the university system
2. To continue the data analysis of the Needs Assessment survey being done by CASS
3. To formalize the working symposia to be conducted during the fourth quarter of this year

CURRENT STATUS OF CURRICULUM DEVELOPMENT

The development and expansion of university curriculum to include information on the aging/developmentally disabled has been completed through the first stage of development. Thirteen courses have either been added or modified and two other courses are in the planning stage for development during the coming year.

The next stage of curriculum development, the evaluation stage, will be initiated during the fall of 1978.

CURRENT STATUS OF NEEDS ASSESSMENT SURVEY

The CASS project responsible for conducting a survey in Region 6 concerning the needs of all developmentally disabled persons has been completed through the first stage of data analysis. A report on the initial findings of this needs assessment was presented by Jim Wood at the annual meeting of AAMD in Denver during May.

CASS continues to provide information and technical assistance to consumer groups and service providers of local, state, regional and national levels.

CURRENT STATUS OF WORKING SYMPOSIUM

The first of the working symposia to be held in Omaha on August 17 is in the final planning stages. Participants have been invited from a wide

variety of professionally based agencies and should prove to be a most rewarding experience for those who are involved.

ACTIVITIES COMPLETED THROUGH JUNE 30, 1978

Papers Presented

Kallstrom, Lee A., "Curriculum Development for Personnel Involved with the Aging Developmentally Disabled," Paper presented at the National Conference on Developmental Disabilities and Gerontology. Ann Arbor, MI: May, 1978.

Wood, E. James, "Comparison of Community Versus Nursing Home Services for Aging Developmentally Disabled," Paper presented, AAMD, Denver, May, 1978.

Kallstrom, Lee A., "Providing Services for the Developmentally Disabled Aged," Paper presented, First World Congress on Future Special Education, Sterling, Scotland: June 27, 1978.

PLANS FOR JULY 1 - SEPTEMBER 30

Major goals for the next three months will include the completion of the first working symposia, the submission of papers for nationally distributed proceedings, and the preparation for continuation of the curriculum development at the University of Nebraska.